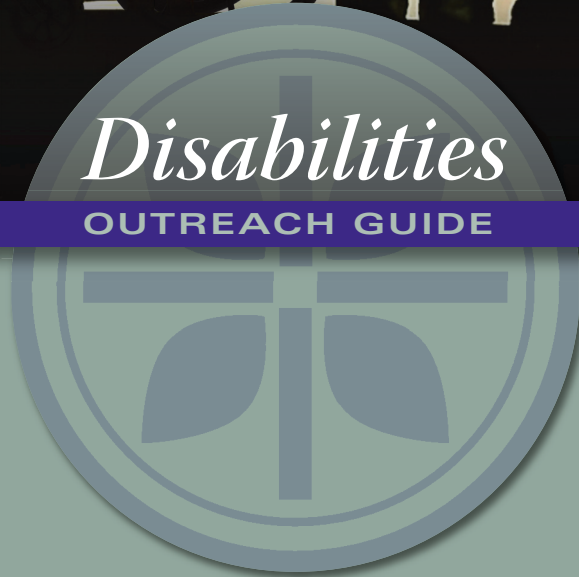




Disabilities

OUTREACH GUIDE



Caring Connections
a program of the
National Hospice and Palliative Care Organization

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I. Overview

A. INTRODUCTION

Many people with disabilities are living longer now with more modern and technological advances in health care, and need different kinds of care and support, particularly at the end of life. In addition, trends show that parents and caregivers of those with disabilities are *not* outliving their children as they historically did in most cases. With the changing trends, hospice providers need to be ready for to care for people with disabilities and their families as well as a child or adult with a disability whose parent is under their care.

Hospice providers reaching out to offer care and services to the disabilities community need to be sensitive to the many issues present for the individuals and their families. Evaluating and determining “quality of life” is a delicate topic, one that within the disabilities community is highly emotionally charged, particularly within the wider scope of end-of-life care. Since “quality of life” is what hospice generally promotes, that message can be viewed as a loaded statement, particularly for the disabilities community.

Also, it is critical to recognize that in the disabilities community, end-of-life care is often synonymous with “ending life.” There have been countless examples of individuals with life-long disabilities, whether physical or developmental, either being given inadequate care or flat-out being denied care when a health care provider determines that it is pointless to provide treatment to someone who has such poor “quality of life.” For example, in 1995, Sandra Jensen was denied a heart-lung transplant by the Stanford University School of Medicine because she had Down Syndrome (*the decision was later reversed*).¹

Even though hospice providers know about person-centered care and recognizing the whole person beyond the disease, one can pass judgment without even thinking about it because of culturally-ingrained prejudices. Most of the experience hospice providers have with disabilities are those that are brought on through the progression of a terminal illness and related to end-of-life care which can be very different matter than a life-long disability.

In this Guide, we have sought to provide a very broad introduction to the most important issues affecting the larger disabilities community, along with specific outreach strategies. Please note that physical and cognitive disabilities could each have its own guide, and for the sake of inclusion, certain sections are focused more closely on cognitive disorders, while others are appropriate only for those with physical disabilities.

¹Stolberg, S.G. (1998, April 5). Ideas & Trends: The Unlisted; Live and Let Die Over Transplants. *The New York Times*.

B. DEFINITIONS

There is no way to provide a comprehensive list of all disabilities and impairments. As a result, the American Disease Association has developed general definitions of both mental and physical disabilities and impairments.

The ADA defines an individual with a disability in three parts. Specifically, an individual with a disability is a person who

1. Has a mental or physical impairment that substantially limits one or more major life activities,
2. Has a record of such impairment, or
3. Is regarded as having such impairment.²

According to the ADA, a **mental impairment** is defined as “[a]ny mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.” Whereas, a **physical impairment** is defined as “any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (*including speech organs*), cardiovascular, reproductive, digestive, genitourinary, hemic and lymphatic, skin, and endocrine.” Ibid.

Neither the statute nor the regulations list all diseases or conditions that make up physical or mental impairments, because it would be impossible to provide a comprehensive list, given the variety of possible impairments.

C. DEMOGRAPHICS

In 2006, the US Census Bureau reported that there were over 51.2 million known persons living with a disability, and that 32.5 million were living with serious, life-limiting, disabilities. That means that the disability community represents 18% of the America population, and the seriously disabled represent 12%. No other minority community represents a greater proportion of the US population.³

Approximately 14.3 million people or 6% of the population reported serious mental illness related to cognitive functioning. This group includes those diagnosed with Alzheimer’s disease, depression, and the mentally challenged. Of seniors, 72% of people eighty and older reported living with a disability.

Signaling that care for the disabled will not end with the Baby Boomers or “Generation X,” in 2006, four million children ages 6-14, or 11% of children were reported to live with a disability. Taking into account non-institutionalized people aged 18-34, 22.2% of people living with a disability attend school. 15.4% are enrolled in college or graduate school. 37.2% of 16-64 year olds living with a disability are employed, while 21.5%, of those 5 years and older, live on or below the poverty line.

² National Institute on Disability and Rehabilitation Research. What is the ADA: Definition of Disability. Retrieved December 5, 2008, from <http://www.adata.org/whatsada-definition.aspx>.

³ US Census Bureau. 2006. American Community Survey on Disability. Retrieved December 5, 2008, from <http://www.census.gov/hhes/www/disability/2006acs.html>.

D. HISTORY

To gain a better grasp on the health care challenges of the disabled, the past can be very informative. As far back as the 1800s, persons with disabilities both mental and physical were labeled as “deviant.” In this era, medical professionals were convinced the only way to “protect” society from these “deviants” was to permanently incarcerate the disabled until death. These medical statements eventually lead to the isolation and degradation of millions.

Originally built to be training schools, asylums quickly became permanent care units for the developmentally disabled. By the turn of the century, public institutions averaged over 500 persons per facility. In 1910, Dr. Henry Goddard developed a new category of mental disability: Moron. He went on to explain that the mentally challenged were victims of heredity, and that their ailments could be directly correlated to poverty, crime, drunkenness and prostitution. After World War II, and the influx of newly disabled veterans, interest groups were established to educate the public about disabilities.

Around the world, a movement brewed that demanded inclusion for disabled people. This movement however did not keep the disabled from being treated as less than human. As recently as 1979, it was legal for certain state governments to sterilize the disabled, for fear of spreading their affliction to future offspring. Having been deprived for decades, the disability community in the 1970s lobbied the federal government for independent living rights, and advocated for legislation concerning those living with debilitating ailments. Eventually, with the help of the Civil Rights movement, they scored their biggest victory with the Rehabilitation Act of 1973. This was followed by the Individuals with Disabilities Education Act of 1975, and most notably the Americans with Disabilities Act of 1990, which secured for the disability community unprecedented access to their civil rights, and thus to the overall society around them.⁴

Currently, the disability population — especially those with Down Syndrome — are living longer and different kinds of care and support are needed now. Even though great strides have been made, there is still a long way to go to insure quality health care for the disabled community.

E. HEALTH CARE DISPARITIES

Though the focus of the guide is end-of-life care, in order to successfully engage in disability outreach it is important to understand the significant health care disparities between those living with and without a disability. A 2004 study conducted by a group of North Carolina physicians entitled “*Health Disparities Among Adults with Developmental Disabilities, Adults with Other Disabilities, and Adults Not Reporting Disability in North Carolina*” found that because of health risk behavior and higher rates of a sedentary lifestyles, persons with disabilities were more likely to report their health status as “fair” or “poor.”⁵ Despite the

⁴ Minnesota Governor's Council on Developmental Disabilities. 2007. Parallels in Time: A History of Developmental Disabilities. Retrieved on December 5, 2008, from <http://www.mncdd.org/parallels/index.html>.

perceived poor health status of many people who have a disability, there is less being done to prevent, and/or treat their health care concerns.

According to the North Carolina study, persons with a disability were more likely to live with chronic diseases such as cardiovascular disease, high blood pressure, arthritis, and diabetes. However, they were also less likely to have had treatment. Below is a comparison of those who live with and those who live without a disability, and the rate of those surveyed who live with chronic diseases. Notice the staggering disparities concerning high blood pressure, cardiovascular disease, and arthritis. Despite almost half of those living with a disability reporting to have high blood pressure and arthritis, there are no statistics to show that they are receiving more care.⁵

Those who specifically live with developmental disabilities are even less likely to receive quality health care. Because of their inability to make informed decisions, many times “potentially harmful and futile” procedures are taken in an attempt to keep the patient alive, or no care will be given at all. Some physicians even see more harm than good being taken from modern medicine increasing the lifespan of individuals living with developmental disabilities.

Women who either have a physical or developmental disease face even stronger health care disparities. Compared to women without a disability, they are less likely to have seen a gynecologist, including routine cervical cancer and breast screenings. More alarmingly, 26.8% of women with developmental disabilities aged 40 and over had never had a mammogram compared to only 13% of women who live without a disability.

Just like any other person, those who live with a disability seek to live a healthy life. Access to medical care has been something the disabled community has fought and secured rights for with the Individuals with Disabilities Education Act of 1975, and the Americans with Disabilities Act of 1990. However, there are still obstacles that hinder complete access to care. Many health care professionals have little experience working with persons living with a disability.

Because of the history and disparities the disabilities community has generally received with their health care needs, it is important for hospice providers to emphasize and reinforce treatments and care provided by their services during life and at the end of life.

⁵ Havercamp, Scandlin, & Roth, 2004. Health Disparities Among Adults with Developmental Disabilities, Adults with Other Disabilities, and Adults Not Reporting Disability in North Carolina. *Public Health Reports* .volume 119, pg 418-26.

II. Disability Focus Group Findings

Please note that these findings only present the viewpoint of people with developmental disabilities and their caregivers who participated in the focus groups.

In December 2006, two focus groups were conducted in Albany, NY for the National Hospice and Palliative Care Organization (NHPCO). The first focus group was composed of high functioning, semi-independent adults with developmental disabilities. The second group consisted of caregivers of lower-functioning adults with developmental disabilities. Group participants discussed their general feelings about end-of-life issues. Participants were then asked to read and react to topics such as advance care planning, end-of-life caregiving, and hospice itself.

A. ADVANCE CARE PLANNING

About half of the functioning adults that took part in the focus group and almost all caregivers were familiar with the term “advance care planning.” Due to previous knowledge or experiences with advance care planning, most surveyed had a positive image of “long range planning.” An overwhelming majority of the functioning adults surveyed liked the idea of gaining control over their end-of-life care. Others were attracted to the idea of getting the hard decisions out of the way as soon as possible. Judith Barr, a high functioning woman from Albany, made a poignant remark when she expressed how she felt once the advance care process had been completed. She said, “I just felt that I could move on with my life now, and I didn’t have to think about necessarily the bad stuff anymore.” One of the strongest feelings gathered from the adults with developmental disabilities was their determination to have the strongest say in their end-of-life care.

Most caregivers surveyed had actually already begun the advance care planning process for themselves, but agreed that advance care planning for their loved one is also critical. One man said about the planning for his son, “That’s the importance of the advance directive. He even included religious considerations in his. What he expects is written down. You feel better and you [feel] like you’re not burdening anyone with making decisions about you.” Although this sentiment echoed through a substantial number of caregivers, some admitted that they preferred to avoid thinking of the future, and would rather deal with end-of-life concerns when they came up. These feelings were further revealed in the direct results of the survey, which showed that caregivers of lower-functioning adults were less likely to have end-of-life wishes for their loved one written down.

When it came to a health care proxy, almost all functioning adults had chosen one. Most were family or close friends. Living with serious conditions, and having experienced health scares those who had not made their choice had already discussed a health care proxy, and considered the option of the utmost importance. One woman, noted that the Terri Schiavo case had spurred her and her family to discuss who would make health care decisions if she was unable to, settling on her sister. One of the few

differences functioning adults and caregivers had was whether to terminate life support or not. Most functioning adults held reservations about giving up before all had been done. One adult said, “They can pull the plug but only after they have done everything.” In contrast, most caregivers were more pragmatic about life support. The overall attitude was that caregivers wanted to hold on to memories of their loved one living life, not “laying [in] a coma for whether it’s one day, a week, [or] whatever.”

Caregivers agreed that the decision would not be an easy one, but they would want the same for themselves if ever in a prolonged life support situation. One of the most common themes of both surveys was that talking about advanced care planning and learning more about it helped those who had previously not thought about it make informed decisions.

B. END-OF-LIFE CAREGIVING

Most surveyed agreed that they had heard of end-of-life caregiving. Most functioning adults however saw the term “end of life” in a negative way. Seeing it as “cold” and “depressing” the majority considered the “end of life” a lonely dark place where no one cared about your life anymore. Ironically, few had either discussed or even thought of end-of-life care before the survey, and once they had a chance to talk about it, and hear from people with first-hand experience their initial reaction changed. On the other hand most caregivers seemed more comfortable with the idea of end-of-life caregiving. Citing previous discussions with health care professionals about end-of-life care for their disabled loved one, caregivers are much more focused on diverting the attention away from “End of Life” and on to “Care.”

Caregivers were also given an end-of-life information sheet and asked to comment on what they thought could improve its effectiveness in the disabled/caregiver communities. One of the main suggestions was to alter the language when talking about the end of life. One caregiver explained, “For many of us with children with multiple disabilities, the end of life could be something that you know could happen at any time.” “Pass-on” is an alternative phrase used by one caregiver. Another caregiver suggested that the hospice community consider changing “end-of-life care” to “care giving for your loved one with developmental disabilities at the end of life.”

C. HOSPICE

Of all topics hospice was the most known. Many of the focus group participants had either first or second hand knowledge of the hospice experience. One adult man, who had lost his fiancé sometime ago, said hospice provided him with “a lot of closure.” Though it still hurt, he was grateful of the hospice experience. Others had a different opinion. Both caregivers and functioning adults had misconceptions about hospice. The idea that hospice is where you are sent when there is no hope left was reverberated throughout both caregivers and the adults. There were even rumors that in some hospices patients were denied some or all of their medicine, making for very painful ends of life. As in most community circles, the misconceptions of hospice were in large part due to the role hospice has been given in the public eye: a place where the sick go to die. Two of the functioning adults made the comment that they believed that



hospice hastened death, and that they wanted to stay as long as they could. Nearly all of the negative feelings towards hospice hinged on the lack of firsthand knowledge

Most caregivers and functioning disabled adults with first-hand hospice experience viewed it more positively. Describing their experiences as “caring” and “compassionate,” many caregivers were more than satisfied with the role hospice played in the death of a love one. One woman even says that the hospice nurse in charge of caring for her mother-in-law dispelled any misgivings she had, and fourteen years later they still speak on occasion.

D. MEDIA AND MESSENGERS

When it comes to information and support, the majority of functioning adults and caregivers would first turn to family members, friends, or trusted organizations. There were two adults who said they would not know who to turn to, and one said she would search the Internet, although she knew of no Website offhand. Most however, would rely on close friends and family. One adult woman talked about how she was there for her friend during the death of her father. “When she lost her dad we talked about it a lot and it was like unexpected, he just died, it wasn’t a planned or expected that he was going to die. So we had a long talk about it then.” One thing that is clear is that few people would turn to doctors for support or information. Adults describe interaction with doctors as far from positive. They feel doctors are quick to dismiss their opinions, which is frustrating for most, especially when control is so important to them. Caregivers are even less trusting of doctors. From their experience, they feel that doctors are not always knowledgeable enough about developmental disabilities – not just at end of life, but “all through life.”

Caregivers agreed that their first choice for support and/or information would be other caregivers. This is a consistent assertion, given the caregiver’s need to be fully understood. Other than caregivers themselves, family members caring for the low-functioning disabled adult also rely on trusted organizations and the developmentally disabled community for support and information. Caregivers describe the developmentally disabled community as a strong network of organizations that are well equipped to help disseminate information on these issues. There is also a high level of trust between these organizations and the people they serve, which will provide an unknown organization or coalition like yours with much needed legitimacy and weight in the community.

III. Strategies for Reaching Out to the Disabilities Community

Outreach to the disabilities community needs to begin with a comprehensive focus on two key areas: education and partnership. Hospices can benefit from listening to all those who actually are members of the community, are closest to it, or are experts in the field — consumers, families, advocates, professionals and the organizations that support them. They are the ones who truly understand the nuances, and can help you learn what you need to know in order to communicate effectively and serve compassionately.

As you begin to reach out, begin by using an open inquiry to build partnerships throughout the disabilities community and ask “What are your issues and concerns, and how can we help?” For the most part, there seems to be little overlap between the end-of-life and disability fields, making it that much more important to share experience and expertise. To help bridge the gap, this section provides specific strategies that will help your organization reach out and increase your access to the disabilities community in your area.

A. GET PREPARED

As with any outreach plan, in order to be successful in your efforts, you can begin by getting organized, ensuring support, and developing a thoughtful and detailed plan. When reaching out to the disabilities community, you can also be very mindful of the complexity of the issues. Prepare yourself and your team thoroughly, and focus on building lasting links between your hospice and your disabilities community members.

- **Evaluate resources.** Assess your existing resources, both personnel and financial. Is your staffing structure such that you can conduct active outreach, and then support the new clients you may bring in? Is the overall financial health of your organization solid enough to take on a change in census? Your very first step should be seeking a solid understanding of where you are in order to fairly evaluate where you might go.
- **Gather support, form a team and develop a plan.** Ensure that your senior leadership and all levels of staff are on board with your disabilities community outreach plans. The entire organization needs to be engaged and share the same vision of inclusiveness and growth. Form a team made up of staff as well as a wide range of disabilities community members and enable this core working group to support your primary outreach liaison, if you have one. Establish a reasonable plan of action, based on your planning team’s assessment of short and long-term goals, expectations and priorities. Potential action steps are listed on the following pages.
- **Recognize the complexity on many levels.** Disease management is complicated, and disability of any kind adds extra dimensions and layers to the experience. This can include who funds the care (*and whether funds are even available*), which agencies are involved, how and whether facility staff provide care, which caregivers have the true, legal voice, whether there are concerns about withholding treatment and “ending life” prematurely, concerns about assisted suicide and euthanasia, who will care for survivors (*when they also have a disability*), and so on. We will address all of these points throughout this guide.



B. SEEK UNDERSTANDING

When reaching out to the disabilities community, try to understanding of the myriad issues and needs that are an integral part of it. Use this guide only as an introductory educational tool and keep building your knowledge, pursuing all avenues of information to get informed and prepared.

- **Gather information.** Consider a variety of means to learn more about the disabilities community, and what the wants and needs are, by holding individual interviews, organizing focus groups or conducting community surveys. In addition, you will find a wealth of information on the Internet (*e.g., disease-specific Web sites, advocacy blogs*), within the community (*e.g., support groups, educational tools*) and in publication (*e.g., medical journals, general literature*), so gather your data in a number of ways and from many different sources.
- **Honor the disabled community and acknowledge their struggle for social justice.** For those with life-long disabilities, acknowledging their struggle for basic rights is an imperative. Honor their voices and their struggles, and be sure to ask and hear what they want. Allow as much room as possible for making preferences known, and include them in all decisions. Respect what they want to do, from very small to very big things. Remind them that as you face the end-of-life together, you will help them maintain their independence and autonomy. And for those who can express their own wishes, be mindful that they've been involved in medical decision-making their entire lives, and may know much more about health care as a whole, as well as their own care (*based on what has worked or not worked in the past*) than you expect.
- **Recognize that the dying process is particularly difficult for the disabilities community.** For many disabled persons, there have been countless instances when they faced health care crises and were told they were imminently dying, or worse, were urged to consider just giving up and letting go. So when true end-of-life nears, it is particularly difficult for those who have spent a lifetime focused entirely on fighting it. It is also especially challenging for caregivers (*family or facility-based*), who are rarely trained in death and dying, and have also been a part of the life-long struggle against injustices and premature "ending of life" on behalf of their loved ones/clients.

Dr. Gloria Ramsey, JD, RN, a nationally recognized expert in bioethics, nursing education, and health disparities, as well as a professor with the **Uniformed Services University of the Health Sciences** in Bethesda, Maryland, suggests a creative way to gather information and learn about the disabilities community. She says, "Consider attending one of the annual 'Abilities Expos,' held in different locations across the country about three times a year. The Expos, billed as shows for independent and assisted living products and services, have grown over the years, and attract consumers, families and providers. The education components are extensive, and include seminars on everything from advance care planning to the benefits of adaptive sports, along with technology demonstrations and advocacy tips. An Expo is simply a great educational tool on many different levels for anyone involved or interested in disability issues."

- **Set aside preconceived notions and be careful about passing judgment.** Cultural bias towards the disabilities community is often so ingrained that we are not even aware of how acutely it affects our decisions. So when working with the disabilities community, refrain from making your own judgments about what kind of life (*and suffering*) this person has had. Be careful about presuming that “all dying people are disabled and so I have experience with them already,” given that a stable disability, whether cognitive or physical, is very different from progressive and terminal disease. Also, be mindful about making assumptions about what they feel, or judging their quality of life.

C. BUILD PARTNERSHIPS

The foundation of your outreach can be built on the relationships you develop with the disabilities community – meaningful, long-term partnerships that benefit both you and the wider community. This means reaching out to all those who have a stake, a voice, a need or an interest in the field in some way. Everyone has a role to play, a skill to share, a perspective to consider.

- **Develop the relationship before you even need one.** Initiate meetings with the leadership of local disabilities groups (*e.g., agencies, facilities, support groups*) to find out what their needs are around end-of-life care. Before you make the call, think about what you can offer this specific group. Or the community at large. One suggestion is to invite a cross-discipline team to review the summary of the focus group results (*as provided in Section II*) to see the types of needs that you might be able to help meet. Explain what your hospice can do for the community and that your role is to help them and support their families and other caregivers. Getting involved and developing good relationships early on with all pertinent groups will help build trust for long standing partnerships.
- **Invite everyone to the table.** Consumers, families, professionals, disability advocates, service providers, agencies ... are all members of the disabilities community, and therefore, needs to be a part of the conversation. More often than not, disabilities and end-of-life providers do not end up at the same table and the two groups remain separate and apart. To bridge the gap in your community, set up conversations with individuals who work in the disability communities as well as individuals with a disability or their family caregivers to discuss ways your organization can support them. Be sure to meet with

Angela King, Director of Development for **Volunteers of America**, emphasizes the need for reaching out ahead of time. “Your best long-term strategy is to build a partnership well before it’s needed. Providers who may be involved in community groups control the selection of hospice, and can supply ongoing referral opportunities. So it’s an excellent business decision that also results in better care, with everyone understanding his/her role. Individual needs are always different. It could be a group home or family home or someone living independently. Typically you’ll be working with the individual or the family, but more often with a state agency or a case worker. Approach it as a systems issue.”



people representing the range of disabilities — the spinal cord injury specialist has very different experience and perspective than the autism spectrum specialist. Have these conversations in a place and within time constraints that are appropriate, and commit to meaningful engagement, repeated over time.

- **Make the connection.** There are a multitude of organizations both within your community and nationally that serve the disabilities community. Learn about them, attend meetings, request personal appointments, and start linking up. Be careful that you find the right contacts, and identify which organizations truly want to partner with you.

The type of active organizations will vary by community, so find out which ones are local and appropriate for you. In addition, some agencies focus more on education and employment, while others provide hands-on care, so the type of relationship you build with each one will be different. See the “Resources” section of this guide for more details on the below groups and more.

- ◆ Administration on Developmental Disabilities
- ◆ The Arc of the United States (state and local chapters)
- ◆ Association of University Centers on Disabilities
- ◆ Departments of Developmental Disabilities
- ◆ National Association of State Directors of Developmental Disability Services
- ◆ Disability Rights Advocacy Groups (*e.g., Not Dead Yet*)
- ◆ Disability Rights Education and Defense Fund
- ◆ National Organization on Disability
- ◆ National Council on Disability
- ◆ Public/private support groups
- ◆ Service providers and other agencies that serve the local community

D. EDUCATE AND TRAIN WITHIN THE DISABILITIES AND HOSPICE COMMUNITIES

Build knowledge and awareness. Ensuring true understanding of hospice and palliative care is an ongoing challenge, not just for the disabilities world but for the wider community. On the flip side, end-of-life care professionals are sometimes unaware of the intricacies of the disability experience, and have much to learn from local experts as well as people with disabilities and family caregivers. Staff, family and community trainings that explain the benefits of hospice as well as the details of disability issues throughout the lifespan, are all part of this important strategy.

- **Acknowledge and share expertise.** Address the concerns (*and misconceptions*) that a potential partnering organization may have about hospice, conceding that you do not know all the intrinsic needs of the disabilities community. Then help to provide a better understanding of hospice services and how both agencies can work together to provide their own expertise and support.

While there are some residences, particularly traditional group homes, where the staff may be younger and have little or no experience with death and dying, many personnel will be experts in working with their clients. Remember that some clients, if they're living in a facility, may have lived there for a very long time, and so the staff knows them as well, or better, than family members. Acknowledge the role of facility caregivers who are like family to their clients. Remind those involved that you're there to help take care of the person together and to partner in providing the best care possible for the client and their family.

- **Host reciprocal trainings.*** With the partnerships that you have built, a next logical step is hosting training sessions, sharing the expertise that staff members have in their fields. Depending on your audience (*staff, families, consumers, the general public*), topic suggestions include the specifics of both fields, communication, assistive devices, special medications, grief and loss, levels of understanding on death and dying (particularly for those with cognitive disorders), spirituality and religion, health care proxies and guardianship, and so on. Planning and organizing a joint training can serve as an excellent opportunity to bring your community together.

MaryBeth Schneider, Assistant Executive Director for **Direct Support and Self Advocacy for NYSARC, Inc.**, whose organization represents service providers supporting people with intellectual and other developmental disabilities, shared an advocacy monograph with NHPCO. The result of a recent collaborative effort by NYSARC, Inc., the Hospice and Palliative Care Association of New York State and the New York State Developmental Disabilities Planning Council focuses on building systems capacity for the end-of-life care field and people with disabilities. The monograph states, "In order for the fields of developmental disabilities and hospice to come together successfully, they must first understand each other's structure and services. [...] When working in concert, hospice and developmental disabilities service providers can create an environment that addresses the needs of the dying person in a way that makes sense for the person, adds resources to the residential team caring for the person, and provides follow-up grief counseling to all those involved."

***Please see the Appendix on page 34 of this guide for a sample training curriculum for hospice and disabilities experts.**



E. CLARIFY BILLING AND FUNDING

Even for patients with private insurance, billing and funding are complex and potentially problematic matters. As with everything, it's best to address the issues before they become too difficult and unmanageable. Gather the most current and relevant information, and establish contacts who can help you navigate the system.

Brian Jones, CEO of Hospice and Palliative Care of the Ohio Valley, Inc., shares that he's had well-intentioned people tell him, "We lose money when we have your patients." Further, he acknowledges that "indeed, if the individual facility or agency is not experienced with hospice, billing issues can be very complicated, and initially, it might result in a loss of revenue for them. We have to work hard to explain the benefits and why the funding side of this shouldn't deter them from our services." He goes on to say, "If there is a perception that money is going to be lost, then of course they'll only call in hospice at the last minute. But with the right information and contacts, you can get reimbursement and will not lose money. So bring up billing issues right away."

- **Tackle the billing questions up-front.** Unfortunately, one of the biggest barriers to hospice care for the disabilities community is billing. Many facilities or agencies feel that they're going to lose money if they work with agencies like hospice that are funded by Medicare. Because this can prevent or delay calls to hospice it is important to address this issue early in your partnership, acknowledge it and clarify the realities from the outset.
- **Establish close contacts with local Medicare and Medicaid offices.** Since there can be confusion among the disabilities community about the Hospice Medicare Benefit, establish contacts within the local Medicare and Medicaid offices themselves. Many people with disabilities may already be receiving some Medicaid benefits, and there is often a perception that one will cancel out the other, or that certain services will be excluded because benefits are already in place. Further, each state has a different plan (*e.g., fee for service, managed care*), or in some cases, has incomplete hospice coverage, so the state must take on a much larger portion of the payment. Check with your local Medicare and Medicaid offices, and be sure that both you and the disabilities providers have the most current information available. If possible, try to identify an advocate in the system in the state Medicaid office who can help you navigate through potentially complex bureaucracy.

F. COMMUNICATE APPROPRIATELY

For those with only mild cognitive disorders, and certainly for anyone with a physical disability who has no cognitive impairments, the honesty and openness of your conversation should be no different than those with other clients. For those with a more serious cognitive disorder, or anyone who is deaf or hard of hearing, you will want to work with their caregiver or sign language interpreter to communicate. Learn effective ways to connect and communicate with the disabilities community and how to utilize the wide variety of assistive devices available.

- **Don't underestimate the ability to comprehend.** When speaking with someone with a cognitive disability, be aware that they think more concretely, so be direct and clear, and do not use euphemisms or beat around the bush. Speaking frankly is actually a part of everyday communication — there is no need to couch statements or gloss things over. Once you get a good understanding of the person and gather their personal history, you will be able to communicate well in many different ways, respecting their interests and concerns, and helping with the challenges of end-of-life.
- **Be patient.** For an individual with a cognitive disorder, it may take them a little while to grasp the specifics of a situation. People with mental retardation, for instance, learn slowly. Give them time to try to understand on their own, and with the assistance of their caregiver, follow-up to evaluate their degree of comprehension (if their disability is more acute, you may need to work directly with their caregiver). Be patient – it may simply take longer to explain things to everyone.

Bill Gaventa, MDiv, of the **Elizabeth M. Boggs Center on Developmental Disabilities at the Robert Wood Johnson Medical School** in New Brunswick, NJ, suggests using resources that are already available within the community to enhance understanding and communication. One such option is "*The Ten Commandments for Communicating for People with Disabilities*," an entertaining and engaging tool for developing a basic level of understanding and skill about the disabilities community. The video takes a light-hearted look at general attitudes, offering suggestions for better communication that will help people overcome their awkwardness and reservations about the disability "factor."
[Note: this video is available from Amazon.com]

In addition, care plans are necessarily more complex. This is as a result of the extra team members involved, the fact that some patients can't speak for themselves (*or at all*), and concerns about comprehension and the ability to express pain. The care plan should therefore include specific details on the best ways to communicate.

- **Learn how to connect.** Hospice staff may have experience working with diminished capacity resulting from the progression of a terminal illness, but life-long disability presents a new set of learning opportunities. When communicating and working with someone with a disability, don't assume that they need or want your help with certain tasks as many adults with disabilities want to be treated as independent people. Be sensitive about physical contact; avoid touching an individual's wheelchair, scooter or cane, as their equipment is part of their personal space. And always speak directly to the person with the disability, not to his/her companion or aide. For more information on how to specifically connect, please review the "Disability Etiquette" guide written by the United Spinal Association at www.unitedspinal.org/pdf/DisabilityEtiquette.pdf.



- **Become familiar with assistive technology, mobility devices and service animals.** There are a wide range of assistive options that offer independence for people with disabilities and ease communication. Educate yourself about this wide range of technology, and take advantage of the ones that are designed to facilitate communication. Whether someone is completely deaf, or has been in a wheelchair their entire lives, or relies on an animal to summon help in the event of a seizure, these resources facilitate everyday living and are simply a part of who they are, and something to become familiar with.

Brian Jones, CEO of **Hospice & Palliative Care of the Ohio Valley, Inc.** in Owensboro, KY, shares his organization's efforts to increase communication with the hearing-impaired. He says, "We purchased 'pocket talkers,' assistive devices that allow individuals to communicate with people who are hard of hearing. A small microphone picks up speech, which is amplified and sent to a hearing aid-compatible earphone. For patients who are not totally deaf, it enables much better communication. And they're not very expensive. Every hospice should have some. It's so much better than shouting at our patients who have hearing loss, or just choosing not to communicate because it's too difficult."

G. FOCUS ON PERSONAL EMPOWERMENT

Planning ahead is a smart idea for everyone. Putting wishes in writing is an empowering act, and ensures that choices and decisions will be honored, should an individual not be able to speak on their own behalf. A written life review is another wonderful way to chronicle life details, serving a dual purpose of empowerment and information-sharing for the entire team.

LaDonna VanEngen, Hospice Program Coordinator with **Saint Elizabeth Hospice** in Lincoln, Nebraska, suggests that "While more and more providers are getting advance planning done, and maybe half of facility residents will have some paperwork signed, it's the easier things, like burial details, that are more often addressed, as opposed to issues like extraordinary measures, which are so very complicated and end up getting left undone. For those with life-long disabilities, it is so critical that these matters are dealt with outside of the stress and panic of crisis."

- **Emphasize the need for advance care planning.** As with the general population, it is always wise to plan ahead. However, for those who do not speak for themselves, or who have had life-long struggles to ensure that their rights are honored, advance care planning can be a difficult subject. Ultimately, the most vital question to address is what the person's goals are relative to their current condition and should a new medical diagnosis or terminal illness emerge. Keep the focus of the conversation on planning ahead for health care wishes before a crisis situation occurs.

- **Record more than the technical things.** Writing a “Legacy Letter” or creating a Memory Book is a wonderfully therapeutic project that can be shared between patient and caregiver. While serving as a positive life review, it also functions as a practical tool for the entire team members. It provides a record of important events in the person’s life and sheds light on their personality, enabling everyone involved to know them better. It can also help the primary caregiver come to terms with their own loss, when that time comes.

Leigh Ann Kingsbury, a gerontologist and disabilities expert, recently developed a person-centered manual entitled *“People Planning Ahead: A Guide to Communicating Healthcare and End of Life Wishes.”* It is written specifically for people with cognitive disabilities to help them plan and make decisions throughout their lives as they need increased support, and/or are dying. It is an excellent tool for those who do not already have plans in place, and even for those who do, but have not addressed health care or end-of-life issues. In describing her project, Ms. Kingsbury writes, “As more and more people with labels of intellectual and developmental disabilities are welcomed into their communities and are living in communities of their choosing; [This manual] came out of a recognition that we need to do ‘full circle planning.’ If one has a well developed person-centered plan, then much of the information we need about one’s values, one’s goals for one’s life and possibly one’s end-of-life, already exists. We only need to take the planning a few steps further . . . and apply that information to health care decision making and if need be, end-of-life decision making.”

H. WORK WITH “FAMILY”

All caregivers, including facility staff, have a vested interest and play integral roles in the lives of their loved ones or clients. The lines between client and family may get blurred, especially when an individual has lived for most of their lives in a facility and has either no or few family members actively involved in their lives. Be sensitive to staff “family,” and especially alert to the dynamics that may play out if/when uninvolved biological family members resurface. Also, be prepared to work more frequently with health care proxies or state-appointed guardians as this situation can be more prevalent with people with disabilities.

- **Recognize that facility staff members sometimes become the person’s family.** In some instances, when an individual has been living in a home or facility for a number of years and has little contact with his/her biological family, the staff members there assume the roles not only of primary caregivers, but of “family.” This “family” structure in the residence also provides an entire social network. As discussed earlier, remember that the staff caregiver, sometimes clinically trained, will feel strongly that he/she is the best one to provide care. So as much as you can, do allow facility caregivers to be involved in care.



- **Be mindful of the biological family's role.** In some cases, less frequently today than in the past, an individual with a profound disability was sent away to an institution, and did not have any contact with his/her biological family. Often, too, the family would sign rights over to the state to act on behalf of their loved one. When the biological family retains legal surrogacy but there is no advance directive, they have the true, legal voice in health care decisions, regardless of their previous involvement (*or lack thereof*). The legal rights of family must be respected, even when it is clear that residence "family" know the client better and would honor wishes better than the biological family.
- **Expect to work with health care proxies and/or guardians.** Many people with cognitive disabilities without close family will have a state-appointed health care proxy or guardian. In some cases, the residence director serves in this role. This is a legal process that is much more common within the disabilities community. While most proxies or guardians are competent and advocate on behalf of their clients, some may not have been involved in the person's life. Or, they may not understand the benefits of hospice care at the end-of-life, and will not seek it out on their client's behalf, either at all or soon enough.
- **Anticipate new challenges when the primary caregiver of the person with the disability becomes a hospice patient.** As trends change, and adult children with disabilities outlive their parents/primary caregivers, there is far greater of a concern about what will happen to the child when the parent is dying. Parents who've spent years advocating for community/home-based options for their children are now worrying about what will happen when they face their own end-of-life. The hospice team can anticipate that the entire family will have significant needs, including potential residence placement for an adult child who may not be able to live independently.

Angela King with **Volunteers of America** shares a caution about uninvolved family who show up in the last minute and cause great difficulties. "Be careful with 'Swoop Down Families,' a term we use for biological family who come and sweep in the last minute, accusing facilities of inferior care, but who haven't been seen in years and know neither their loved one nor the level of care that has been provided for so many years. If end of life is near, they try to make decisions without any real relationship and based on no real information. They put everyone in a panic, because of concerns about legal issues; they may even threaten to sue. Of course, blood relatives have the say, but when they've been absent for so long, who is the real "family" and who should therefore advocate on behalf of the patient? These cases can result in protracted legal battles, and are very painful for everyone involved."

I. RECOGNIZE THE ROLE OF GRIEF AND LOSS FOR BOTH THE INDIVIDUAL AND THE FAMILY

As with any loss, bereavement needs to be attended to, yet for some people with developmental disabilities, grief and loss issues can re-surface in ways that professionals often misinterpret. In addition, families have dealt with loss their entire lives, from the moment of diagnosis through life-long crises. As you reach out, be particularly sensitive to this and prepare to offer bereavement support and resources.

- **Bereavement can be different for those with developmental disabilities.** Everyone grieves in his/her own way, and at his/her own pace. However, for those with developmental disabilities, as a result of some limited cognitive understanding, their expression of loss may not become evident for some time, or it may not be understood. Professionals can watch carefully to interpret behaviors that may initially appear as “acting out,” but are actually expressions of grief. As with anyone, a “Loss Assessment” conducted during admission/intake can offer information about previous loss experiences and how the patient/family reacted at the time. This serves as a living document for staff to help them understand behaviors as they emerge.
- **Empathize with a family’s history of loss.** Parents with disabled children tell us that they have experienced grief from the day they first learned of their child’s disability — grief over the struggles that may and do emerge, grief over the “ordinary” life that is not to be. Parents, siblings and extended family struggle to provide care for their loved ones, and experience challenges of many kinds on a daily basis; health care-related crises are often the most prevalent. Throughout the course of their lives, their grief is often unrecognized and unaddressed by the system. As you are providing care, be mindful of the history of loss that these families experience.

Jeffrey Kauffman, LCSW, a nationally-respected author and leader in the field of developmental disabilities, has consulted with more than 25 mental retardation agencies in direct grief support services for staff and clients, training, and program development. He shares that “loss often originates in things that happened very long ago. Frequently in residences, old losses come up as if they’re fresh. Those losses are many, and are often linked to broken relationships such as death, moving away, or a sense of rejection. Any kind of a change is a struggle because there is such a strong need for constancy and habituation. Behavioral problems and the modification techniques that staff are accustomed to using can blind the helper to recognizing the true meaning behind the behavior. It’s an expressive language; behavior expresses the real feelings. The prescription is addressing the pain and meaning of an earlier loss.”

James Brooks, Executive Director of **Project Compassion** in Chapel Hill, NC, shares the words that a father revealed to him about his experience with grief. “We still clearly remember the day about 25 years ago when my wife and I were told by a doctor in a hospital that our child had a disability. All [the doctor] said was, ‘Your child has such and such, and ... we’ll get back to you.’ We left the hospital and sat in our car and just cried. No one gave us any more information or reached out to help us. No one acknowledged how difficult it was going to be to watch our child struggle so profoundly in life. We never really received any support, making the initial news and our ‘loss’ that much more painful.”



J. ORGANIZE JOINT DISABILITIES AWARENESS AND END-OF-LIFE EVENTS

After you have had the chance to learn about the disabilities community and build your partnerships, consider organizing a joint awareness event of some kind. You might host or allow your partner agency(ies) to do so. Make it broader than just information-sharing and use it as an opportunity for community building!

- **Figure out what's doable.** Talk to your partner and together decide where you want to exert your energy first. Limiting your initial focus to a specific group within the disabilities community might be most practical. Collaborate with your new partner(s) and explore what resources you have to enhance your event. Think through all the details of what your message is, and what kind of community service you hope to achieve, beyond basic education about both fields. Potential topics to develop your initiative around include advance care planning or patient care advocacy.
- **Build bridges.** Spend a lot of time building bridges, assembling your task force, and cultivating relationships that will support your initiative. Any project that blends the end-of-life and disabilities worlds together will take time. Find and include experts in both fields. As a collaborative effort, you will be working to bring together groups from many different places, perhaps for the very first time.

James Brooks shared the details of an event that **Project Compassion** designed to initiate dialogue between end-of-life care practitioners and the disabilities community. "We began by organizing a team of 25 community leaders – professionals, consumers and parents – and met every other month for a year before holding our first public event. Early on we wanted to make sure that our efforts were rooted in the community, and that we weren't duplicating anything already being done. We did an environmental scan, bringing people to the table with relationships in the developmental health field. The strongest voices came from parents caring for adult children with disabilities, and adults with disabilities themselves, expressing concern about who will care for them? This guided us, and our theme was reflected in our title, 'What Will Happen to Me? A Workshop on End-of-Life Issues for Persons with Developmental Disabilities.' The one-day event was held in April 2008 in Chapel Hill, NC, and was designed specifically for consumers with developmental disabilities, their family and friends, and professionals to explore important issues related to end-of-life care, and offer tools and strategies for planning ahead. (See more information under 'Model Programs.')

In summary, consider this work as an opportunity to build community, as well as to truly think holistically about bridging the gap between end-of-life care practitioners and the disabilities community. As you team up, do so in a way that involves the widest number of players possible. Community gets created through the diverse organizations that support it. Caring Connections has a number of resources that can guide you throughout this process. Please visit www.caringinfo.org/community for more information.

IV. Model Outreach Programs and Initiatives

A. VOLUNTEER OPPORTUNITIES: HOSPICE OF CENTRAL IOWA, PERRY, IA

With a background as a case manager for people with disabilities, as well as a domestic and sexual assault counselor, Lois Hoger, volunteer coordinator for Hospice of Central Iowa, has helped develop an innovative program that trains people with disabilities to become hospice volunteers.

In 2004, Hoger was invited to a meeting between Woodward Resource Center staff (*a residence that serves people with disabilities*) and Hospice of Central Iowa management to look at developing a hospice volunteer training for the Woodward staff. The goal was to have trained hospice volunteers on staff who would be able to assist residents who might need hospice services some day. It soon became apparent that there was a conflict of interest for those staff members already working with patients, and so the project was expanded to residents, so they, too, could support their peers should hospice care become necessary. Special trainings were designed to enable residents to assist all hospice patients, not just their own peers.

Hoger says, “I’m very familiar with this population and felt comfortable developing the program. We’ve done a lot of tweaking over the years, and it continues to evolve. It serves as a wonderful link between our hospice and a facility that serves people with disabilities. One of the many benefits is engaging the wider community — some Woodward staff serve as local area hospice volunteers, and bereavement experts not connected with either organization volunteer their time to help with the trainings.”

Some of the highlights of the program include:

- Inviting Woodward resident volunteers to special project gatherings in the hospice facility. These include printing birthday and Christmas cards that are sent to patients, and designing and making May Day baskets and 4th of July flag gifts for patients. The 4th of July flag gifts were distributed to a local nursing home by the resident volunteers themselves, the first time the volunteers were engaged in a project outside of the facility.
- Inviting all the Woodward resident hospice volunteers to the annual hospice volunteer banquet. There are usually over 300 volunteers present, and two tables are reserved for the Woodward volunteers right in the middle of the banquet area, so they really feel a part of the program.
- Reviewing training basics at every visit — what they should be doing and what it means to be in hospice care. The one area that requires extra time is the death and dying conversations. Most of the resident volunteers have experienced a loss of a loved one, but it is obvious that few have spent time processing that loss. It always comes out in training conversations.



- Requiring that each resident volunteer has his/her own picture name tag. They are worn when doing hospice work, just like all of the other hospice volunteers.

To learn more, contact Hospice of Central Iowa at 800.806.9934 or visit www.hospiceofcentraliowa.org.

B. “WHAT WILL HAPPEN TO ME?” COMMUNITY EVENT: PROJECT COMPASSION, CHAPEL HILL, NC

Following the death of both of her parents, Debbie Kohler, a woman living with developmental disabilities, felt unprepared and alone. She wondered: “What will happen to me?” Inspired by Debbie and her story, Project Compassion, an end-of-life care coalition in Chapel Hill, NC, created an initiative in 2006 to help people living with developmental disabilities, their families and professionals understand and anticipate end-of-life issues.

Project Compassion began by forming a team composed of people living with developmental disabilities including Debbie, as well as parents, volunteers and professionals from the developmental disability world and the end-of-life world to identify the key issues and to plan community engagement efforts. This task force was chaired by a social worker with a passion for these issues. Team members met every other month for a year to educate each other about the issues and build their network. One key activity the group did early on was to watch the film *“Without Apology”* together to learn more about the history of developmental disability services, including the role of institutionalization, and the changes that have occurred thanks to the individual, family and professional advocacy. Through this planning process, the group came to a consensus not to focus on telling the historical story but to look at current issues and challenges as well a future options.

The first public event the group planned as called *“What Will Happen to Me?...A Workshop on End-of-Life Issues for Persons with Developmental Disabilities.”* The audience was mixed, including parents, consumers and professionals. Held on Saturday, more than 80 people participated: 10% consumers, 40% parents, 50% professionals. The primary focus was on grief, focusing on grief issues that consumers, parents and professionals face and how best to support them through grief. In addition to grief, a sessions covered end-of-life planning issues for consumers and for parents of consumers.

Based on the program’s evaluation, the response was very positive. Consumers and family members acknowledged and discussed the many grief and losses they have faced in their journeys and the barriers to thinking about end-of-life care. They discussed the importance of looking ahead. Many professionals from the developmental disability world had not had the opportunity to explore how consumers experience grief and how to support them through life transitions, including preparing for end of life. Several professionals realized for the first time that some behaviors by people with developmental disabilities labeled as inappropriate may be connected with grief. The behavior may change when appropriate grief support is offered. All participants learned about specialized resources and support for planning ahead that all families of people with developmental disabilities need.

In addition, based on the positive feedback from this event, the task force has formed a Speakers Bureau on the diverse topics related to developmental disabilities and end-of-life issues to educate area professionals. The group also is planning a follow up event for consumers and family members that will include more education about health care issues, legal and housing issues. **To learn more, go to Project Compassion at www.project-compassion.org.**

C. TICKET TO WORK: NEBRASKA HOSPICE AND PALLIATIVE CARE PARTNERSHIP, NE

In 2006, the Nebraska Hospice and Palliative Care Partnership (NHPCP) and the Nebraska Department of Health and Human Services partnered to develop and implement the “Ticket to Work Palliative Care Program.” The demonstration project was designed to give Nebraskans with pain-related disabilities access to palliative care experts and interventions to help them hold their job or return to the workforce.

Prospective program clients receive an initial assessment from teams that include a social worker and a nurse from a local palliative care program. The palliative care program provides medical interventions and comprehensive referrals to community services. The program does not, however, provide direct job placement services. Instead, it incorporates referrals to a variety of existing agencies to support individuals with disabilities who desire to work.

NHPCP first contracted with the team at Saint Elizabeth Palliative Care in Lincoln, NE, who saw the first client in December 2006, then hired a coordinator for the Ticket to Work Palliative Care Program in May 2007 to coordinate. In February 2008, the program expanded to include four counties in northeast Nebraska through Siouxland Palliative Care. The program is expected to expand to western Nebraska in 2009.

The Ticket to Work Palliative Care Program is funded by a federal grant awarded to the Nebraska Department of Health and Human Services from the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services. NHPCP, a nonprofit 501(c)3 organization, is Nebraska’s hospice and palliative care association. **Additional information can be found at www.nehospice.org.**



D. BUILDING COMMUNITY: HOSPICE AND PALLIATIVE CARE OF THE OHIO VALLEY, KY

As a local hospice provider, staff at Hospice and Palliative Care of the Ohio Valley tried to identify minority populations in their service area that they believed were underserved for hospice care. They identified the Wendell Foster Center (www.wendellfostercenter.org) as a potential partner in increasing access to the developmentally disabled population. The Wendell Foster Center is both a residential campus as well as has an outpatient facility for therapy. After a couple of face-to-face meetings and several email exchanges about increasing access, the hospice found that billing was a concern for the Center as an inpatient care facility. The billing personnel from both organizations worked together to help overcome that particular hurdle. During those meetings, Center staff expressed concerns about past ramifications to the facility from the state when residents die there. These concerns had led to a routine practice of sending imminently dying residents to the hospital.

Brian Jones, CEO of Hospice and Palliative Care of the Ohio Valley, explained that “Our relationship with the Wendell Foster Center allowed them to keep patients at their ‘home’ to die. To keep a relationship going with them, we utilize some of their higher functioning residents to assist us in work around our office since it was important it was for their residents to volunteer in the community. While we have only had a couple of patients through this partnership, it has increased awareness and access to hospice services. It has also demonstrated how two non-profit entities, serving two very diverse populations, can partner together to improve access and care to all.”

For more information, contact Hospice and Palliative Care of the Ohio Valley at 800.466.5348 or visit www.hospiceohiovalley.org.

V. Resources for Disabilities Outreach

The list of resources, organizations, advocacy groups, Web sites and literature for the disabilities community is immense. Please note that for every disability there may be multiple sources of information. Below is a brief list that focuses on issues and resources for a broad range of people with disabilities and their families.

A. PROFESSIONAL ORGANIZATIONS

American Academy of Developmental Medicine and Dentistry (AADMD)

www.aadmc.org

is an organization of physicians, dentists, students, and advisory members, whose collective mission is to work together, as clinicians, educators and advocates, utilizing our respective expertise and talents, to improve the overall health of children and adults with developmental disabilities.

American Association on Intellectual and Development Disabilities (AAIDD)

www.aaidd.org

is the professional association run by and for professionals who support people with intellectual and developmental disabilities. AAIDD promotes progressive policies, sound research, effective practices and universal human rights for people with intellectual and developmental disabilities. See Position Statement: "Caring at the End of Life," available at www.aaidd.org/content/170.cfm?navID=31.

American Association of People with Disabilities (AAPD)

www.aapd.com

is the largest national nonprofit cross-disability member organization in the U.S., dedicated to ensuring economic self-sufficiency and political empowerment for the more than 56 million Americans with disabilities. AAPD works in coalition with other disability organizations for the full implementation and enforcement of disability nondiscrimination laws, particularly the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990.

The Arc of the United States

www.thearc.org

is the world's largest community-based organization of and for people with intellectual and developmental disabilities. It provides an array of services and support for families and individuals and includes over 140,000 members affiliated through more than 850 state and local chapters across the nation. The Arc is devoted to promoting and improving supports and services for all people with intellectual and developmental disabilities.



The Association of University Centers on Disabilities (AUCD)

<http://www.aucd.org/template/index.cfm>

is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. Programs are located in every U.S. state and territory and are all part of universities or medical centers, and serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change. AUCD is a resource for local, state, national, and international agencies, organizations, and policy makers concerned about people living with developmental and other disabilities and their families.

The Center for Practical Bioethics

www.practicalbioethics.org

is a nonprofit, free-standing and independent organization nationally recognized for its work in practical bioethics. The Center helps patients and their families, health care professionals, policymakers and corporate leaders learn more about ethically complex issues in medicine and research.

Disability Rights Education and Defense Fund, (DREDF)

www.dredf.org

founded in 1979 by people with disabilities and parents of children with disabilities, DREDF is a national law and policy center dedicated to protecting and advancing the civil rights of people with disabilities through legislation, litigation, advocacy, technical assistance, and education and training of attorneys, advocates, persons with disabilities, and parents of children with disabilities.

The Hastings Center,

www.thehastingscenter.org

is an independent, nonpartisan, and nonprofit bioethics research institute founded to explore fundamental and emerging questions in medicine, health care, biotechnology. Much of the Center's research addresses bioethics issues in three broad areas: care and decision making at the end-of-life, public health priorities, and new and emerging technologies.

National Alliance of Direct Support Professionals (NADSP)

www.NADSP.org

is a coalition of organizations and individuals committed to strengthening the quality of human service support by strengthening the direct support workforce. The Alliance is staffed by representatives from the fields of mental health, developmental disabilities, child welfare, education, and many others in the human services community.

The National Association of State Directors of Developmental Disabilities Services (NASDDDS)

www.nasddds.org

is a nonprofit organization that seeks to promote and assist state agencies in developing effective, efficient service delivery systems that furnish high-quality supports to with intellectual and other developmental disabilities. In pursuit of this goal, NASDDDS strives to provide member state agencies with timely analyses of federal statutory and regulatory policies that affect people with disabilities; disseminate cutting edge information on state-of-the-art programs and service delivery practices; provide technical assistance and support to member states; and offer a forum for the development of state and national policy initiatives.

The National Organization on Disability

[*www.nod.org*](http://www.nod.org)

works in partnership with businesses, government, national philanthropies and local organizations to promote the inclusion of people with disabilities in U.S. society. The NOD accomplishes this through the creation of some of the nation's most innovative and progressive programs that promote employment opportunities, raise awareness and marshal resources for people with disabilities.

Not Dead Yet

[*www.notdeadyet.org*](http://www.notdeadyet.org)

is a national disability rights group that leads the disability community's opposition to legalization of assisted suicide and euthanasia. Founded in 1996, Not Dead Yet's mission has expanded to leading opposition to other forms of legalized medical killing.

The Rehabilitation Research and Training Center on Aging and Developmental Disabilities (RRTCADD)

[*www.uic.edu/orgs/rrtcammr*](http://www.uic.edu/orgs/rrtcammr)

promotes the successful aging of adults with intellectual and developmental disabilities (I/DD) in response to physical, cognitive, and environmental changes. It's coordinated research, training, and dissemination activities promote progressive policies and supports to maintain health and function, self-determination, independence, and active engagement in life. The RRTCADD is a national resource for researchers, people with intellectual and developmental disabilities, their families, service providers, policy makers, advocacy groups, students, and the general community.

TASH

[*www.tash.org*](http://www.tash.org)

is an international membership association dedicated to building inclusive communities through research, education, and advocacy. TASH members are people with disabilities, family members, fellow citizens, advocates, and professionals working together to create change and build capacity so that all people, no matter their perceived level of disability, are included in all aspects of society.

The U.S. Census Bureau

[*www.census.gov/prod/2006pubs/p70-107.pdf*](http://www.census.gov/prod/2006pubs/p70-107.pdf)

serves as the leading source of quality data about the nation's people and economy. This link is to a document entitled, Americans with Disabilities in 2002 (issued in 2006), and presents a detailed report of the disability community in the U.S., highlighting a wide range of data. In addition, at [*www.census.gov/hhes/www/disability/disability.html*](http://www.census.gov/hhes/www/disability/disability.html), additional reports on current disability data can be found.

The U.S. Department of Health and Human Services, Agency for Health care Research and Quality

[*www.ahrq.gov/populations/disabix.htm*](http://www.ahrq.gov/populations/disabix.htm)

provides a wide range of information and resources for people with disabilities, their families, employers, and clinicians based on extensive research, data, and projects.



B. EDUCATIONAL INFORMATION

Abilities Expo

<http://www.abilitiesexpo.com/IAEBrandManager/v42/index.cvn>

is dedicated to improving the lives of people with disabilities. Abilities Expo is a show for independent and assisted living products and services, and the only one of its kind where attendees can spend hours on the exhibit floor, testing and comparing products and services offered by state-of-the-art exhibitors. Abilities Expo also offers a full line up of free consumer and professional workshops, offered by leading individuals in the health care, education, and retail fields.

Center for Self-Determination

www.self-determination.com

is a Website maintained by a group of individuals and organizations committed to the principles of self-determination. The purpose of the collaborative is to change the nature of the support and service system for individuals with disabilities, using the principles of self-determination to help all persons create the lives they want, connected to and with their communities.

DisabilityInfo.Gov

www.disabilityinfo.gov

is a one-stop interagency portal for online information on Federal programs, services, and resources for people with disabilities, their families, employers, service providers, and other community members.

Last Passages

www.albany.edu/aging/lastpassages

a joint project of the Volunteers of America, the University at Albany, NYSARC, Inc. and Marist College, is a Project of National Significance funded by the Administration on Developmental Disabilities and the Project on Death in America. Its purpose is to share information and promising practices to enhance end-of-life care for persons with developmental disabilities. Available on this Website are a number of resources, including programs, interventions and services for supporting staff, individuals and families dealing with loss and grief, as well as legal, medical and administrative information for advance care planning.

The State of the States in Developmental Disabilities www.cu.edu/ColemanInstitute/stateofthestates

is a research project administered by the University of Colorado, and established to investigate the determinants of public spending for mental retardation/developmental disabilities (MR/DD) services in the U.S. The project maintains a 26-year longitudinal record of revenue, spending, and programmatic trends throughout the country. Analysis of the rich detail of the database reveals the impact over time of federal and state fiscal policy, and illustrates important service delivery trends in the states in community living, public and private residential institutions, family support, supported employment, supported living, Medicaid Waivers, demographics, and related areas. Research results can be found in the many articles, newsletters, monographs, technical reports, and congressional and judicial testimonies available on this Website.

a 21-page booklet that provides a brief overview of eleven Federal laws that protect the rights of people with disabilities and provides information about the federal agencies to contact for more information.

C. LITERATURE RELATED TO DISABILITIES AND END-OF-LIFE CARE

Articles

Ansberry, C. (2008, April 29). When crisis hits the disabled. *The Wall Street Journal Online*. A8.

Derksen, J., Chochinov, H.M. (2006). Disability and end-of-life care: Let the conversation begin. *Journal of Palliative Care*, 22(3), 175-182.

Gaventa, William, C. & Coulter, David, L. (Eds.) (2005). End-of-Life Care: Bridging Disability and Aging with Person-Centered Care. *Journal of Religion, Disability, and Health*, 9(2). Available to order from Haworth Press, www.HaworthPress.com.

Ghan-Shyam, L., Tan-Figueroa, L., Crinella, F.M. (2003, January-February). End-of-life care for a man with developmental disabilities. *Journal of the American Board of Family Practice*, 16(1), 58-62.

Stein, Gary L., "Advance Directives and Advance Care Planning for People with Intellectual and Physical Disabilities," U.S. Department of Health and Human Services/Assistant Secretary for Planning and Evaluation (2008 DHHS electronic publication), at <http://aspe.hhs.gov/daltcp/reports/2007/adacp.pdf>.

Stein, Gary L., "Providing Palliative Care to People with Intellectual Disabilities: (Research Report) Services, Staff Knowledge, and Challenges," *Journal of Palliative Medicine*, 11:9 (2008): 1241-1248.

Tuffrey-Wijne, I., Whelton, R. (2008). Palliative care provision for people with intellectual disabilities: A questionnaire survey of specialist palliative care professionals. *Palliative Medicine*, 22, 281-290.

Books/Magazines/Journals

Abbatiello, G., Faulkner, L.R. (2008). *Hospice and Palliative Care and Developmental Disabilities: Making the Connection*. NYSARC, Inc.: Albany, NY.

Cohen, J. (2003). *Disability Etiquette: Tips on Interacting with People with Disabilities*. United Spinal Association: Jackson Heights, NY.

Force, Lawrence T., Abbatiello, Geraldine, Doka, Ken, & Faulkner, L. (2004). *Trainer's Guide: End of Life Care: Supporting Older People with Intellectual Disabilities and Their Families*, Albany, NY: New York State Arc.



Van Dyke, L. (2003). *Lessons in Death and Grief: Supporting People with Developmental Disabilities in the Healing Process*, Homewood, IL: High Tide Press. Available to order from www.hightidepress.com.

Disability Studies Quarterly (DSQ)

www.dsqsds.org

is the journal of the Society for Disability Studies (SDS). It is a multidisciplinary and international journal of interest to social scientists, scholars in the humanities, disability rights advocates, creative writers, and others concerned with the issues of people with disabilities.

Exceptional Parent

www.eparent.com

is a magazine that provides information, support, ideas, encouragement and outreach for parents and families of children with disabilities, and the professionals who work with them.

Advance Care Planning

Kingsbury, L.A. (2007). *People Planning Ahead: A Guide to Communicating Healthcare and End-of-Life Wishes*. *People Planning Ahead* is a planning manual designed to gather and organize the information needed for health care decision making and/or care at end of life. It is designed for para-professionals, professionals and families who support individuals with intellectual and developmental disabilities. For more information or to order a copy of *People Planning Ahead*, contact Leigh Ann Kingsbury at lakingsbury@suddenlink.net.

Thinking Ahead: My Life at the End workbook and DVD are designed specifically for people and by people with developmental disabilities that enables them to make their own decisions regarding health care treatment and related decisions at the end of life. It contains words, symbols and pictures that facilitate discussion with and decision-making by persons with developmental disabilities regarding their values, goals and treatment preferences at the end of life. The DVD serves as a simple instruction manual, containing vignettes that illustrate in simple, graphic format the purpose and use of the materials. The workbook is also available in Spanish and Chinese. To order a free hard-copy of the *Thinking Ahead* workbook and DVD, send an email to info@finalchoices.org. For more information about this resource and the California Coalition for Compassionate Care's developmental disabilities initiatives, visit www.finalchoices.org (under 'Events and Projects').

D. CARING CONNECTIONS CONSUMER RESOURCES

Website

www.caringinfo.org

- Provides free, easy-to-read information and resources on end-of-life topics
- Download legally valid, state-specific advance directives
- Preview all Caring Connections brochures

HelpLines

Caring Connections HelpLine: 800.658.8898

Multilingual HelpLine: 877.658.8896

Trained HelpLine staff are available to help people find information including:

- Locating a hospice, palliative care program, or other end-of-life care organization
- Free state-specific advance directives
- Brochures
- Information about state and community end-of-life coalitions
- Identifying local, state and national resources

Brochures

Caring Connections provides practical resources to help consumers, patients, and families make informed decisions about end-of-life care. Our materials cover the following topics

- Advance Care Planning
- Caregiving
- Hospice & Palliative Care
- Pain
- Grief & Loss

Brochures are available to view at www.caringinfo.org and can be purchased online at NHPCO's Marketplace (www.nhpco.org/marketplace).

Lotsa Helping Hands

www.caringinfo.lotsahelpinghands.com

An easy-to-use, Web-based resource for friends, family, colleagues, and neighbors to assist caregivers in need.

Partnership for Parents

www.partnershipforparents.org / www.padrescompadres.org

An online support program, available in English and Spanish, for parents caring for children diagnosed with a serious illness that was developed by the Children's Hospice & Palliative Care Coalition.



VI. Acknowledgments

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VII. Appendix

A. TRAINING CURRICULUM FOR HOSPICE AND DISABILITIES SERVICES PROVIDERS

The training curriculum* below was developed by:

Gary L. Stein, JD, MSW

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(Gary Stein was formerly Executive Director of New Jersey Health Decisions)

*Required course for New Jersey Bureau of Guardianship Services/Public Guardianship System.

Suggested content/topics for:

Hospice staff

- Understanding Guardianship
- Medical Issues for People with Developmental Disabilities
- Communication Skills with People with Intellectual Disabilities; Grief and Bereavement
- Developmental Disabilities Through the Lifespan

Disabilities services staff

- Understanding hospice and palliative care
- Separate sessions for: medical and administrative directors; and clinical, case management, and other direct service staff

PALLIATIVE CARE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Course Overview

Day 1:

- Special Needs of People with Developmental Disabilities
- Principles of Palliative Care and Hospice
- Pain and Symptom Management for Non-Medical Staff
- Complementary Interventions

Day 2:

- Self-Awareness of Personal Experiences and Attitudes
- Self-Care
- Communications Skills



Day 3:

- Health Care Capacity and Decision-Making
- Assessing Capacity Among Individuals with Cognitive Disabilities
- Bioethics, Law, and Policy
- Understanding DNR Orders

Day 4:

- Death, Dying, and Bereavement
- Funeral Practices
- Spirituality, Religion, and Cultural Issues

Day 5:

- Withholding or Withdrawing Life-Sustaining Medical Treatment
- Conflict Resolution and Mediation Skills

DAY 1 SPECIFIC CONTENT/OBJECTIVES

Session: Principles of Palliative Care and Hospice

Objectives:

- Special needs of people with developmental disabilities regarding palliative care and hospice
- Define palliative care
- Define hospice care
- Describe the goals and philosophy of palliative care and hospice
- Identify the family as the unit of care
- Describe the physical, psychological, social, and spiritual needs of patients
- Define the family and identify the characteristics of families
- Identify the tasks of the family and the factors affecting family adjustment
- Describe the role of the interdisciplinary team in palliative care and hospice
- List the factors that may signal the need for a team approach, and referral to the team
- Describe the interface between the goals of palliative care and the goals of hospice care

Session: Pain and Symptom Management for Non-Medical Staff

Objectives:

- Define pain and discuss the barriers to pain management
- Describe the parameters of pain assessment
- Discuss the various scales used in pain assessment
- Discuss the concept of total pain
- Define the classifications of types of pain
- List the key principles for pharmacologic pain management
- List the various types of analgesics

- Describe common side effects and adverse drug reactions
- Discuss dosage recommendations
- Discuss the concepts of addiction, tolerance, and dependence
- Discuss the non-pharmacologic interventions commonly used for pain management (*relaxation, biofeedback, pet therapy, massage*)
- Discuss the common respiratory symptoms
- Discuss the common gastro-intestinal symptoms
- Discuss common neuro-psychiatric symptoms (anxiety, depression, delirium)

Session: Complementary Interventions

Objectives:

- Understand the role of non-pharmacological interventions
- Review sensory techniques, such as massage, relaxation, aromatherapy
- Creating a stress-free environment

DAY 2 SPECIFIC CONTENT/OBJECTIVES

Session: Self-Awareness, Self-Care and Communication

Objectives:

- Become aware of attitudes
- Become aware of attitudes towards death and the dying experience
- Connect personal experiences of loss with those of clients and their families
- Develop greater comfort making decisions around end-of-life care
- Learn ways in which job responsibilities impact personal well-being
- Enhance stress reduction ability
- Identify barriers to effective communication
- Strengthen interactional proficiency
- Increase assertiveness skills
- Become comfortable raising issues with physicians
- Develop strategies to lessen blocks to effective communication

DAY 3 SPECIFIC CONTENT/OBJECTIVES

Session: Health care Capacity and Decision-Making

Objectives:

- Define capacity
- Discuss components of capacity
- Assessing capacity among individuals with cognitive disabilities
- Understand barriers to capacity
- Understanding levels of capacity
- Elements of informed consent



- Degrees of cognitive limitations
- Understanding surrogate decision-making standards (substituted judgment, best interests standards)

Session: Assessing Capacity among Individuals with Cognitive Disabilities

Objectives:

- Understanding the role of behavioral staff in conducting assessments of capacity
- Understanding techniques of assessing capacity among people with cognitive disabilities and limited verbal skills
- Discussion of differing levels of capacity
- Assenting to care vs. consenting to care
- Facilitating individual input in health care decisions
- Facilitating limited decision-making

Session: Bioethics and Law for Social Workers

Objectives:

- Application of social work principles
- Discussion of principles of clinical bioethics (respect, beneficence, justice)
- Discussion of informed consent and elements of consent
- Capacity to make decisions
- Discussion of confidentiality
- Discussion of ethics committees, their roles and functions
- Understanding ethical decision-making (benefits vs. burden analysis)
- Understanding withholding and withdrawal of life-sustaining medical treatments
- Definition of assisted suicide
- Understanding legal and ethical distinctions between palliative care and assisted suicide
- Discussion of the doctrine of double effect
- Application of proposed state regulations
- Understanding advance health care planning (state and federal statutes, health care proxy, living wills)

Session: Understanding DNR Orders

Objectives:

- Discussion of do-not-resuscitate (DNR) and out-of-hospital DNR orders
- Description of what happens during resuscitation
- Understanding when DNR orders are and are not medically appropriate
- Differentiating in and out of hospital DNR orders

DAY 4 SPECIFIC CONTENT/OBJECTIVES

Session: **Death, Dying and Bereavement**

Objectives:

- Death, dying, and bereavement in group living
- Define grief and bereavement
- Bereaving the loss of family and friends
- Recognition of staff grief
- Bereavement among staff
- Stages of grieving
- Understanding types of grieving (anticipatory, complicated)
- Discussion of strategies to support grieving individuals (clients, staff)
- Enhancing coping skills

Session: **Funeral Practices**

Objectives:

- Understanding the after death experience
- Roles of funeral directors and the funeral process
- Sensitivity for cultural and religious differences
- Elements of the funeral ritual
- Body disposition, embalming, cremation
- Purpose of funerals
- Psychological/social/spiritual benefits of the funeral for the mourners

Session: **Spirituality, Religion and Cultural Issues**

Objectives:

- Define spirituality, religion, and culture
- Assessing spiritual and religious concerns
- Assessing role of spirituality among people with cognitive disabilities
- Providing spiritual care
- Respecting religious and cultural traditions
- Discussion of diverse practices and traditions of the major religions



DAY 5 SPECIFIC CONTENT/OBJECTIVES

Session: **Withholding or Withdrawing Life-Sustaining Medical Treatment**

Objectives:

- Understanding what is meant by withholding or withdrawing of life-sustaining medical treatment
- Understanding when withholding or withdrawing life sustaining medical treatment is and is not medically appropriate

Session: **Conflict Resolution and Mediation**

Objectives:

- Strengthen skills in identifying areas of conflict
- Increase comfort level with conflict
- Identify the opportunities for growth in situations with conflict
- Develop expertise in negotiating with other professionals
- Explore role as intermediary between the developmental center and the hospital
- Enhance ability to work with angry family members
- Become comfortable raising potentially contentious issues with treatment team members

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There is no text or other markings on the paper.

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